National Electronic Disease Surveillance System and the Public Health Conceptual Data Model (www.cdc.gov/od/hissb)

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How Public Health Differs from Medicine/Health Care

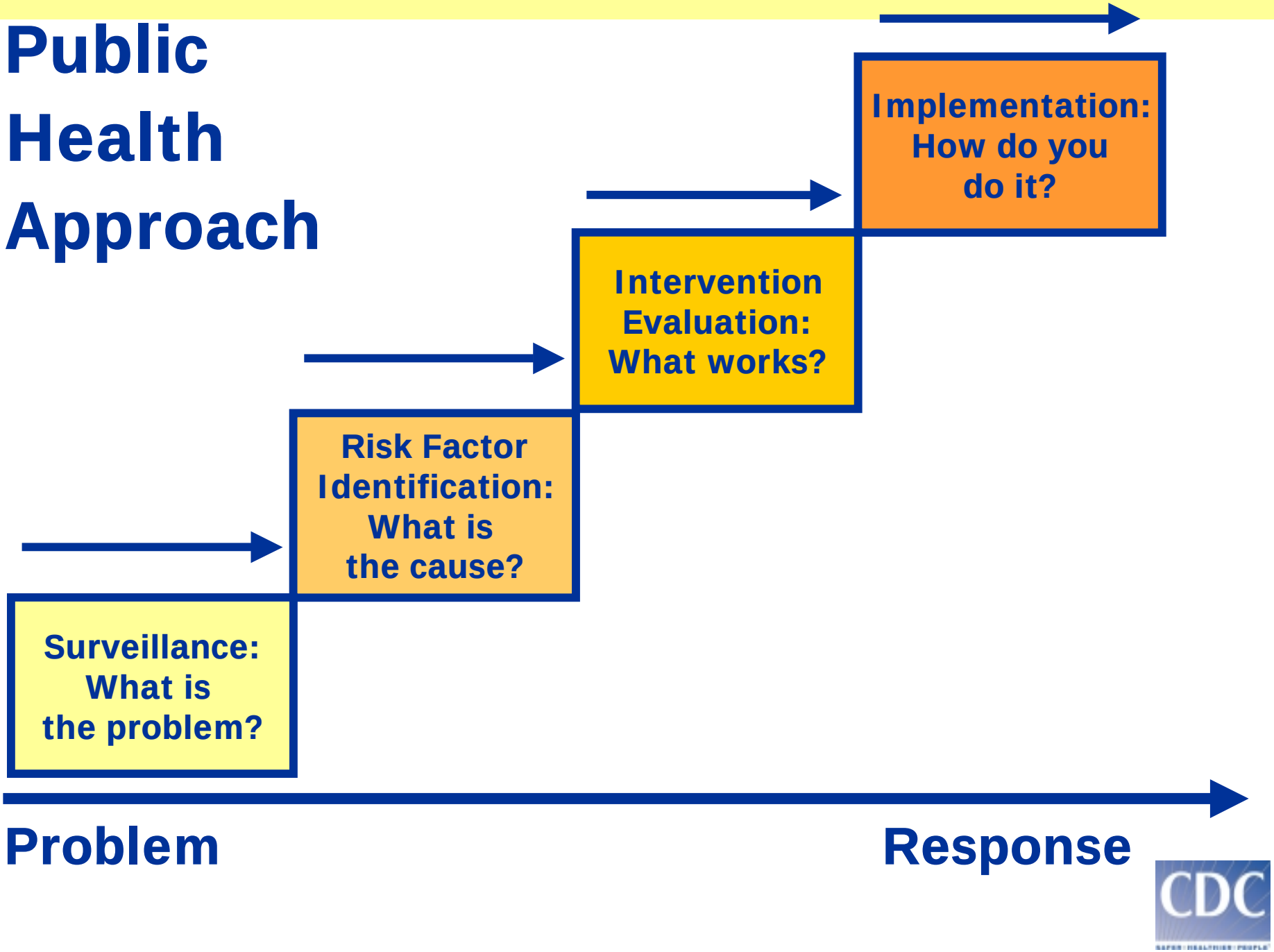
- Focus on health of population
- Emphasis on prevention
- Scope of activities
  - Anywhere in causal chain of disease
- Governmental context

Public Health Surveillance

Systematic, ongoing

- Collection
- Analysis
- Interpretation
- Dissemination
- Link to public health practice

Public Health Approach



Information System Functions Needed for Public Health Preparedness and Response

- PREPAREDNESS REQUIRES THAT ALL PARTNERS--LOCAL, STATE, & FEDERAL-- ARE PART OF SYSTEMS
- Surveillance data analysis--event detection & management (NEDSS)
- Notification—rapid alerting
- Communications –information sharing, not data analysis
- Knowledge management

Current Situation

CDC

Program Specific Reports and Summaries

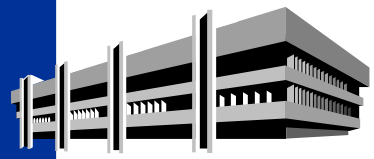
MMWR Weekly Tables

MMWR Annual Summaries

HARS | STD*MIS | TIMS | NNDSS | EIP Systems | PHLIS

Statistical Surveys for Chronic Diseases, Injuries and Other Public Health Problems

Varied communications methods and security - specific to each system - including diskettes, e-mail, direct modem lines, etc.



State Health Department

HARS | STD*MIS | TIMS | NETSS | EIP Systems | PHLIS

Reporting by Paper Form, Telephone & Fax

Data Sources

Physicians

Varied communications methods and security - specific to each system- including paper forms, diskettes, e-mail, direct modem lines, etc.

Chart Review

Lab Reports

HARS | STD*MIS | TIMS | NETSS | EIP Systems* | PHLIS

City/County Health Department

STD*MIS (Optional at the Clinic)

TIMS (Optional at the Clinic)

* EIP Systems (ABC, UD, Foodnet)

CDC

Limitations of current surveillance information systems

- Multiplicity of categorical systems
- Data incomplete, not timely
- Burden on respondents in health care sector increasingly unacceptable
- Volume of data can overwhelm health department capacity
- Systems do not utilize state-of-the-art information technology

Motivators of Change

- Need for more information
- Changing health information policy
- Increasing efficiency
- Evolving technology
- Increasing use of electronic information systems
- Enhancing security/confidentiality

NEDSS long-term objectives

- Ongoing, automatic capture and analysis of data
- Use of data that are already electronic
- System(s) designed on relevant data sources, not diseases
- Integration of public health and health care systems

Example From the Future

- Patient sees physician with respiratory symptoms
- Differential diagnosis pops up (including anthrax)
- Tests are recommended (measles IGM for rash, fever; CXR for pneumonia)
- Test results, diagnosis *automatically* sent to public health

Example From the Future

- Automated tracking of drug resistance among isolates
- Increasing resistance to antibiotic, “P”
- Pharmaceutical data bases: Increase in sales of “P”
- Notice to healthcare providers
- Educational campaign

How are we getting there from here?

- Standards, standards, standards
- Pilots to connect with health care system:
  - Labcorp sending standard files to 7 states
  - Quest sending standard files to 6 states
- Architecture built on Integrated Data Repository, so that data received from health care system can go in single format to single receiving point
- Collaborative approach across categorical programs
- Sophisticated security standards to maintain public health track record in protecting sensitive data

NEDSS Approach

- **Capture data electronically *now* and learn how to use, *AND***
- **Influence how and what data are collected** *a priori*

Pilot Projects

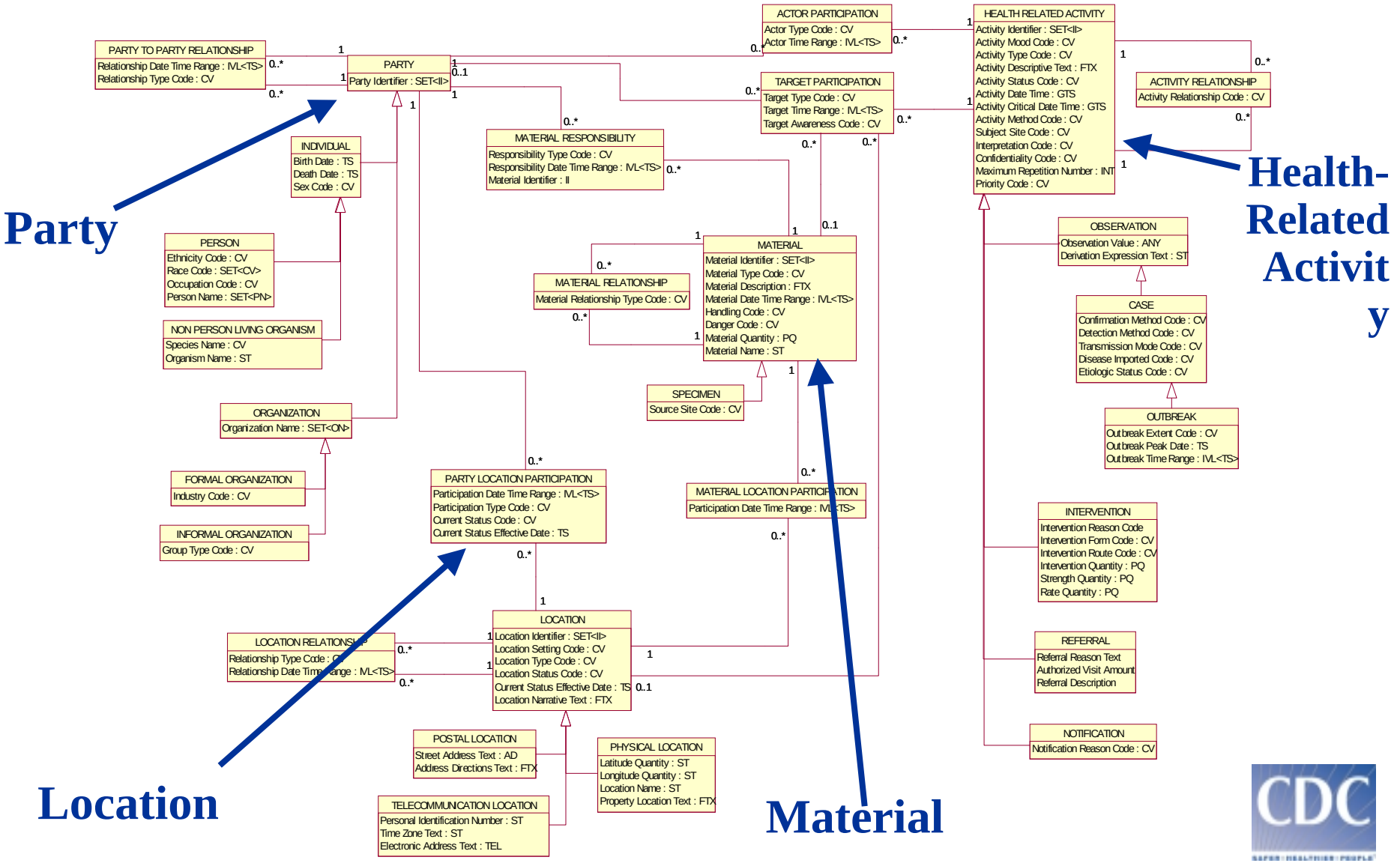
- Electronic Laboratory Reporting Pilots
  - 325 cases via ELR versus 156 on paper (Effler et al JAMA 1999)
- Data Elements for Emergency Departments Pilot Projects
  - Direct reporting from ED to Oregon HD (Kohn et al ICEID 2000 abstract)
- Bioterrorism Pilots
  - "Real-time" surveillance of conditions, syndromes
- Managed Care Projects
  - 18% increase in number of active TB cases detected by HMO pharmacy data review (Yokoe et al, EID 1999)

Public Health Conceptual Data Model

(available at www.cdc.gov/od/hissb)

- Definition of the categories and kinds of data needed for public health (surveillance)
- Diagram showing relationships between them
- Conceptual data model
- Inputs included Australian and Canadian models, HL7 model, Missouri model, CDC systems

Public Health Conceptual Data Model

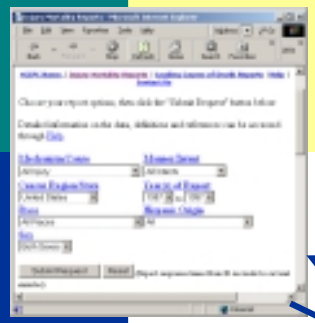


Public Health Conceptual Data Model

- Reduce development efforts for computerized systems
- Enhance data exchange capabilities with health care providers and public health partners
- Represent public health data needs to national standards organizations (e.g., HL7)
  - Party includes population groupings
  - Location needs expansion (to find/locate a person or exposure)
  - Materials for intervention not just medication
  - Health-related activity includes reporting

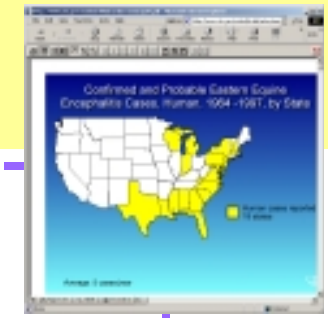
NEDSS State System Architecture Elements

- Web browser-based data entry, management
- Electronic HL7 message processing
- Integrated data repository
- Data translation & exchange
- Transportable business logic
- Data reporting and visualization
- Shareable directory for authorization
- Security system & policies



Local Health Department Or Clinical Site

State Health Department



Reporting, GIS and Analysis

B L

B L

B L

Electronic Laboratory Messages

Integrated State / Local Data Repository

Security

HL7

B L

Clinical Database

XML Data Exchange

Shareable Directory of PH Personnel

CDC and Other Health Depts.

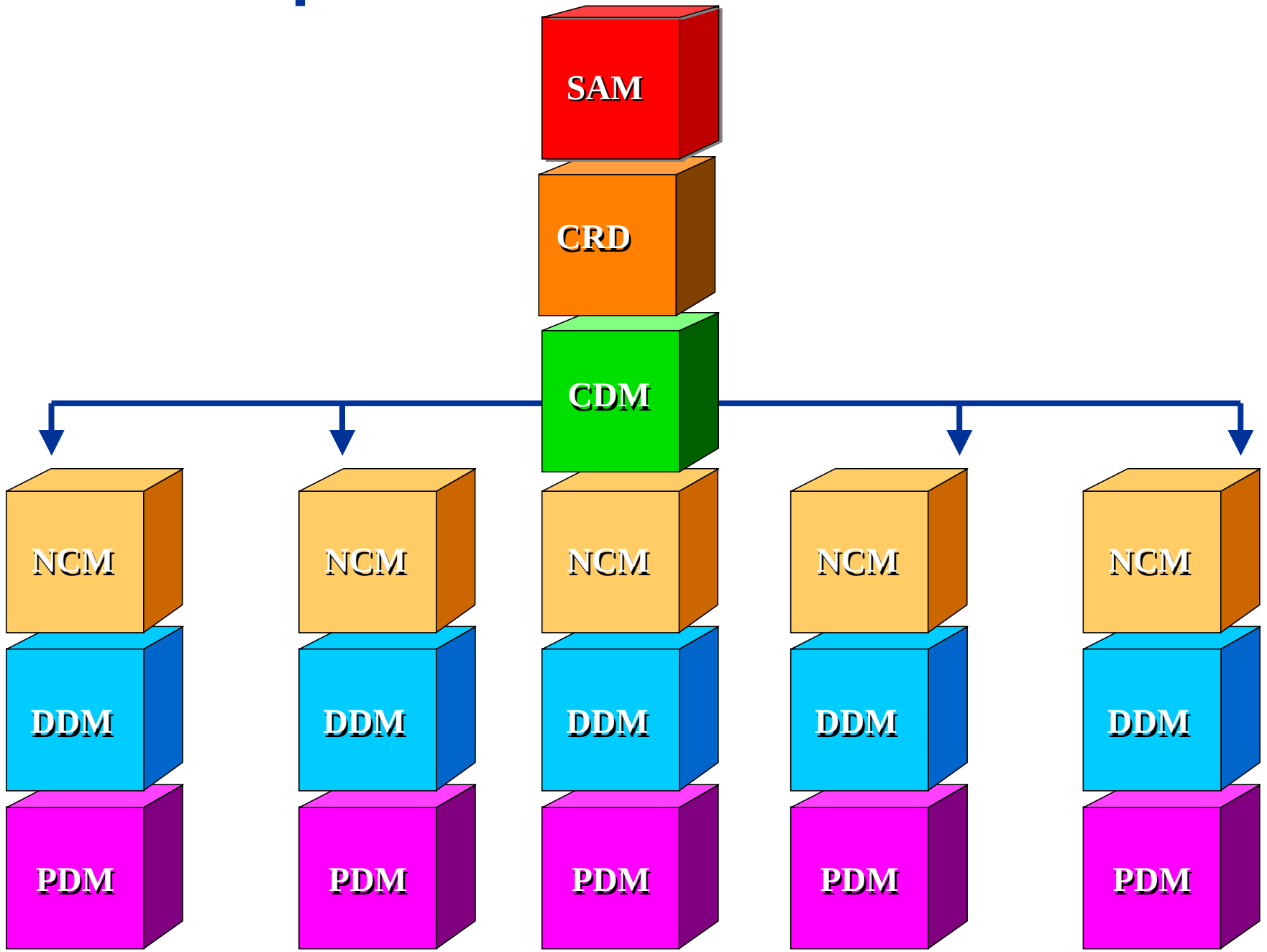
NEDSS System Architecture

CDC

CDC-developed State "Base System"

- "Base system" integration testing– this summer
  - –Core Demographic Module (CDM)
  - –National Notifiable Disease Module (NNDM)
  - –Electronic interchange of laboratory data
  - –Integrated data repository, person-based
  - –Implementation of NEDSS standards
- Base system is platform for other modules
- First step for many states just getting started
- States have option to use (or not) CDC modules

Multiple PDMs from one CDM



Application of PHCDM

- Disseminated model for use/feedback
- Develop conceptual process model (context)
- Implement model (see next slide)
- Coordinate/harmonize with national standards
- Develop change management process
- Integrate efforts of public health partners

Implementing PHCDM

- Developed logical model for NEDSS “base system”
- Develop prototype database design model
- Develop message specifications for data interchange (including vocabulary)
- Apply to systems design
- Disseminate process for mapping systems to model

Barriers / Facilitators

- Privacy concerns
- Data ownership and access issues
- Roles / responsibilities
- Linking systems
- Security
- Data needs and standards
- Electronic medical record
- Internet

Next Steps for NEDSS

- Prototype specifications and standards in new system development—states and CDC
  - Base system integration testing Summer 2001
- Continue to influence standards development organizations to include population health perspective, coordinated with Public Health Data Standards Consortium

Potential Collaborations with EMR Activities

- Pilot projects with electronic laboratory reporting, emergency departments, managed care, pharmacy
- Address technical, standards, and policy issues that emerge from pilots
- Continue to address privacy protection issues